Research Done in "A Good Way": The Importance of Indigenous Elder Involvement in HIV Community-Based Research

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Indigenous worldviews privilege holistic interconnectedness, collaboration, reciprocity, spirituality, and humility, in contrast to Western notions of dichotomous thinking, rationality, and individualism.[1] Within an Indigenous research paradigm, the intentions and process of data collection become as important as the knowledge acquired.[2] Historically, research on North American Indigenous peoples has been carried out almost exclusively by non-Aboriginal researchers, without the active involvement of Aboriginal peoples, and with little or no benefit to their communities.[3,4] (We use "Aboriginal" to refer specifically to First Nations, Inuit, and Métis populations in Canada, and "Indigenous" within an international context.) Consequently, many Indigenous communities distrust Western research. Smith[5] and others[6] have argued for a decolonized research agenda that honors Indigenous approaches to knowing the world. Canada's national research funders are seeking to promote and codify a framework for ethical relationships among researchers and Aboriginal communities.[4(ch9)] As communities are becoming aware of the tension that may exist between biomedical research ethics and their own concerns (for instance, a biomedical emphasis on individual rather than communal harms and benefits),[7–9] they are increasingly establishing their own internal review structures that are more responsive to their local needs.[10,11]

"In a good way" is an expression used by many Aboriginal communities to denote participation that honors tradition and spirit. Among the Anishinaabe people, this is embodied through the Seven Grandfathers Teachings of wisdom, love, respect, bravery, honesty, humility, and truth. From an Indigenous worldview, research done "in a good way" is a sacred endeavor that illuminates the connections between the spiritual and physical world. Elders have a special role to play in this work. Elders

> are people knowledgeable about culture and tradition. . . . Elders are not always persons over a certain age, and not all older persons are considered Elders. Rather, Elders are those who have and show concern for others and the community and show leadership. The position of Elder . . . is one of esteem and respect.[12(p5)]

Elders often provide the wisdom, knowledge, and ceremonial guidance to assist with research processes that respect Indigenous worldviews. Their role in research requires further elucidation.[13–16]

BACKGROUND

In Canada, Aboriginal peoples (First Nations, Métis, and Inuit) experience a variety of health inequities,[17] including overrepresentation in HIV statistics.[18] Risk factors such as intravenous drug use are a large contributor to the HIV epidemic; however, unique determinants of health must also be taken into consideration. These include the history and ongoing legacy of colonization, a continuing devaluation of traditions and languages, and a lack of accessible, culturally appropriate health and social services.[18(p33)] Research with leadership from Aboriginal communities may contribute to reversing these trends.

The Canadian Aboriginal AIDS Network has for over a decade invested heavily in building the research capacity of Aboriginal communities to meaningfully engage in HIV community-based research (CBR). With appropriate adaptations, a CBR approach may assist in decolonizing research practices.[19] The HIV CBR movement in Canada has been a leader in implementing innovative approaches and emergent research methodologies. It comprises a diverse spectrum of populations dealing with a wide variety of ethically complex issues.[20] The movement was one of the earliest to institutionally support collaborative research

Objectives. We examined the role that Indigenous Elders can play in ensuring that community-based research (CBR) is conducted ethically.

Methods. We present data from a larger qualitative study exploring ethical issues that occur in HIV-related CBR through the experiences of researchers engaged in CBR. Between May 2010 and July 2011, we interviewed 51 academic and community research team leaders of federally funded HIV CBR studies. We used thematic analysis techniques to identify themes.

Results. Participating researchers engage Elders in research because Elders are keepers of Indigenous knowledge, dynamic ethical consultants, community protectors, and credible sources of information who are able to counsel and support, mediate conflict, provide local context and history, and conduct ceremonial roles. Potential challenges cited by participants to engaging Elders in research include finding the right "fit," approaching Elders in a culturally appropriate way, and bureaucratic environments that do not honor Indigenous processes.

Conclusions. Culturally appropriate Elder engagement in HIV CBR with Indigenous communities is vital for promoting positive relationships and culturally safe research that respects ceremony and Indigenous ways of knowing. (*Am J Public Health.* 2015;105: 1149–1154. doi:10.2105/AJPH.2014.302522)

approaches and the direct involvement in decision-making of people living with, and affected by, HIV.[21] HIV CBR has yielded effective programs—for example, to reduce risky behaviors for HIV among youths.[22]

Aboriginal peoples have emphasized the need for strong community leadership and the inclusion of First Nations, Métis, and Inuit culture in HIV prevention and treatment programs through various approaches, such as the use of Aboriginal languages to craft prevention messages,[23] peers,[24] sharing circles,[23,25] traditional ceremonies,[26] and the involvement of Elders in prevention efforts.[13,14] The engagement of Elders recognizes their wisdom and their role in preserving the knowledge, history, and well-being of their communities.[15,16] In this report, we examine the role that Elders can play in ensuring that HIV CBR is conducted ethically.

METHODS

The analyses presented in this article draw data from a project[27] headed by the first author. The qualitative study explored the range of anticipated and unanticipated ethical issues that occur in HIV-related CBR through the experiences of community-based and academic researchers engaged in the process.

Sampling, Recruitment, and Interviews

We purposively sampled recipients of HIV CBR grants funded by Health Canada and the Canadian Institutes of Health Research between 1999 and 2006 to reflect regional diversity and the priority populations identified in national HIV policy documents. We e-mailed potential participants to ask if they would participate in the study. We were unable to locate a few of the community leaders who had left their positions; one researcher declined to participate. We sent participants a project description and consent form by e-mail. Interview times and locations were subsequently negotiated.

We conducted semistructured interviews between May 2010 and July 2011. We interviewed (in most cases separately) academic and community co-lead investigators, or their designated project representatives, about ethical issues they encountered. The interviews lasted between 1 and 3 hours, depending on the level of HIV CBR experience. We audio-recorded the interviews with the participants' permission. We

conducted most of the interviews in English; 3 were done in French. Half the interviews were by telephone, half in person. Although some contextual cues may be lost in phone-based interviewing, other studies have found it to be comparable in terms of data quality.[28–30] The interview protocol contained 4 sections, with questions about participant training and experience, how they became involved in their respective project(s), how the ethics review process unfolded, and what kinds of issues emerged over the course of the project.

Data Analysis

We transcribed interviews verbatim. We managed data with NVivo 9 (QSR International, Melbourne, Australia). The research team developed an initial coding framework based on the CBR literature, research team members' experiences with HIV CBR, and emergent themes established through an initial reading of a subset of transcripts. We used thematic analysis techniques to identify major themes in the data.[31–34] We later revised the scheme at an investigator data analysis retreat.[35] Given the research team's significant experience in the area of CBR and ethics review, we considered this process as a form of member checking. Member checking (or sharing preliminary analyses with members of those groups from whom the data were originally obtained for feedback and discussion) is a strategy used by many qualitative researchers to improve validity and credibility.[36,37] Data were independently coded by at least 2 research assistants. An inclusive model of coding was adopted by the team: anything coded under a particular theme by either reviewer was included in analytical discussions. All data related to HIV CBR with Aboriginal communities (a major code) were rereviewed by a subcommittee of research team members, Aboriginal students, Aboriginal community partners active in the HIV CBR movement, and 2 Elders. This team (listed as authors herein) held several conference calls to define the scope of this report, review drafts, and discuss framing and implications. For further methodological details, see Guta et al.[38]

RESULTS

We conducted 50 interviews (with 54 participants). We excluded 3 interviews with

funders from this analysis because the content of their interviews did not include relevant themes. Participants were assured confidentiality. Consequently, given the small potential sample pool, we report limited demographic information. The final sample comprised a diverse group of academics, researchers in community settings, service providers, community advocates, clinicians, and graduate students (Table 1). Many participants had several roles over the course of their careers, and some strongly eschewed a community–university dichotomization. We categorized participants using the role they were in at the time of the interview; however, many had experience in both community and academic settings, and many also defined themselves as community members. They were diverse in terms of regional location, disciplinary focus and area of practice, applied training, and lived experience with HIV. Most had worked on multiple HIV CBR projects; more than one third (35%) discussed their experiences working in partnership with Aboriginal communities. Several voluntarily self-identified as Aboriginal.

Engaging Elders

Participants offered various reasons for engaging Elders in HIV research. Many noted the central role of Elders in Indigenous life as knowledge keepers and guides. For them, engaging Elders was simply common sense and part of an Indigenous way of understanding knowledge transmission and an Indigenous worldview. As one noted, "Ethics isn't just about pen and paper; it's about a way of thinking about the world . . . [I]t's a way of living." Another said, "Elders . . . are our experts, they are our review boards, they're our academics, they're the people that have the knowledge."

Another researcher described Elders as dynamic ethical consultants who can assist with microethical decision-making in real time:

> [W]e have always included Elders because . . . involving Elders, ensures that every step along the way . . . they're there to ensure that those processes are good for the people . . . and when there are ethical dilemmas or decisions that come up that they can provide wisdom and guidance to those situations.

For these participants, Elders played an important and integral part as guides and

TABLE 1—Characteristics of Participants From Study of Ethical Issues Occurring in HIV-Related Community-Based Research (CBR) in Canada: May 2010–July 2011

Characteristic	No. (%)[a]
Province or region	
British Columbia	11 (22)
Alberta and Prairies (Manitoba, Saskatchewan)	9 (18)
Ontario	20 (39)
Quebec	7 (14)
Atlantic Provinces (Nova Scotia, New Brunswick, Prince Edward Island, Newfoundland and Labrador)	4 (8)
Professional role at time of the interview[b]	
Professors or clinician scientists	28 (55)
Trainees (postdoctoral fellows, graduate students)	8 (16)
Researchers and coleaders or designates housed in community-based organizations	15 (29)
Participants who reported HIV CBR experience with Aboriginal communities	18 (35)

Note. Some of the interviews were conducted as small group interviews at the request of the interviewees. Participants were purposively sampled academic and community co-lead investigators, or their designated project representatives, of HIV CBR grants funded by Health Canada or the Canadian Institutes of Health Research between 1999 and 2006. The sample size was n = 51.
[a]May not equal 100% because of rounding.
[b]Many participants identified with multiple roles. For instance, some of the professors and clinician scientists interviewed had experience in community agencies or identified as gay, Indigenous, or HIV positive, and felt that their personal interests were strongly allied with those of the communities. Similarly, some participants housed in community organizations had doctoral degrees, and identified with communities in various ways.

leaders for traditional living, and their role as research advisers was an extension of their general community leadership. The rationale was deeply philosophic: Elders naturally have a role in all aspects of life, including the research process.

Others offered more pragmatic reasons. Elders were described as protectors or gatekeepers who could help outsider researchers navigate and show due respect for local policies and practices. "Outsiders" meant either non-Indigenous researchers or Indigenous researchers working outside their own regions, cultures, or territories. One researcher described the process for an outsider to obtain community consent:

> To do the research at all, you have to go to where the people are, and you have to have connections to the people that they have connections to, and [permission] has to come from the people that they know and trust [like Elders], otherwise they're just not gonna do it.

Several participants remarked how key it was to involve Elders in research because they were credible sources of community information who knew best how to share knowledge with their community. They were also understood to be translators of knowledge, skilled at passing on information from generation to generation. As one put it, "[W]e want HIV knowledge to be in our community; we want our Elders to know it and teach us. We don't want workshops coming from somewhere else." Another participant stated:

> [I]f they're involved in those processes all the way along, then they have the ability to translate those various worlds to community, and also from community to university, like both ways, so it's been, for our organization, you know, absolutely essential that we had Elders on staff.

As a result of who they are (credible messengers) and how they communicate (through Indigenous worldviews), Elders are often able to communicate research protocols and findings in ways that make more sense to communities than outside researchers. Consequently, knowledge translation becomes integrated into the CBR process. Many raised the importance of consulting with Elders early in a project and receiving valuable feedback on research design, protocols, and measures.

HIV research often touches on intimate areas (sexuality, addiction, violence), and these issues can be difficult to talk about (and potentially divisive). Numerous participants described how Elders often took on the role of counseling and support for participants and the research team throughout the life of a project, including instances in which participants became upset (e.g., when disclosing experiences of abuse or violence), and as a resource after data collection had ended. Participants recognized the importance of culturally safe supports (e.g., Elders) to help teams navigate tricky discussions and provide individual short-term counseling and local referrals.

> [P]eople will not use those [mainstream] referrals when they're in crisis. They're gonna go find somebody else to soothe that immediate hurt, right? So research that we're involved in, we try and make sure that someone is actually available in the space, y'know? And if that person wants an Elder, then we make sure an Elder is available.

Elders were also seen as important conflict mediators who could talk teams through difficult decisions, assist with tension resolution, and generally provide guidance and support for study participants, as well as "our clients, our members, but also guidance and support for us as staff and for these bigger issues." Their roles as wise members of the community afforded them the respect and stature to address these issues in culturally appropriate ways.

Elders were also perceived as key members of the analysis team. Their contributions were particularly valued given their ability to provide local context and history to personal accounts.

> [P]art of an ethical analysis of particularly Aboriginal people's stories and their information, is that we understand . . . in a cultural context . . . within which, a lot of . . . health behaviors, health management, health care, health burden, all of those things are experienced.

Finally, Elders often took on ceremonial roles. They performed "welcoming" and "wrap up" ceremonies for data collection or analysis sessions so that work could happen "in a good way." They sometimes led smudge ceremonies and prayers, offered healing circles, songs, or sweats, and bestowed ceremonial gifts (e.g., eagle feathers) where appropriate to research team members, participants, or both. These ceremonies helped team members and participants to spiritually ground the work and to heal and celebrate. These rituals help to mesh Western research practices with Indigenous cultural worldviews and traditions.

Potential Challenges of Engaging Elders

Elders are understood to be people who are steeped in their community's culture and want to "selflessly serve" their community. Our participants underscored the importance of acknowledging the great diversity among the Aboriginal community in Canada: "[S]o every community was different, of course, and I think that was something that was really important for our team to [understand]." Thus, an Elder whose teachings resonated in one community may not connect well with another.

Several participants talked about the importance of finding the "right" Elder. They wanted to ensure a good fit between the Elder, the community culture, and the values and mission of their projects. Age, culture, gender, and experience could be important, but values were also significant. There remains a wide range of opinions and political orientations within Aboriginal communities regarding controversial topics such as sexuality, substance use, and harm reduction. Of particular relevance in HIV research, many participants addressed the importance of finding Elders who held positive attitudes toward sexual diversity and expression and were supportive of harm reduction philosophies. Several recounted stories about having to carefully screen Elders. Sometimes, this meant sitting down and having tea with an Elder and talking about the project or views on HIV. Sometimes, Elders were approached because they were already known for being strong HIV prevention and support advocates. One researcher shared stories about the frustrations of working with an Elder who did not share her project's queer-positive values:

> [W]e are extremely cautious since those experiences about anybody that we bring in. . . . Y'know, you need to make sure that the people that we're gonna entrust are going to take care of us, and so for us in the HIV field that means an Elder who's not homophobic, not AIDS-phobic, not transphobic. Y'know, and there are not a lot of them out there, 'cause traditional teachings as they're being remembered by people who were raised in residential schools, y'know, are very [based in Western religions].

Another researcher shared

> There was an Elder once who came, and it was years ago . . . to do some traditional teachings with a bunch of two-spirit people and he basically said, "It's fine that you're two-spirited, just don't act on it."

("Two-spirit people" are considered to have both male and female spirits, and therefore express alternative sexualities or genders).

Finding the right match was seen as critical, but it could be a time-consuming endeavor. Participants described how community coinvestigators often took the lead in finding and approaching Elders. They described how in the spirit of reciprocity, they offered Elders respect, tobacco, sage (used in smudge ceremonies), other gifts, or honoraria to approach Elders "in a good way."

Research organizational structures presented a final challenge to engaging Elders. A few participants shared that it was sometimes difficult to convince funders or universities of the importance of adequately showing appreciation to Elders for their time in culturally sensitive ways. The bureaucratic academic environment runs counter to many Indigenous ways of being in the world. For instance, many universities require signatures, receipts, and social insurance numbers as proof of the transfer of funds; they use the language of paying people for "services provided." However, for many Elders, the appearance of "selling" Indigenous knowledge is antithetical to the notion that cultural knowledge is not a commodity that can ever be owned or sold. Furthermore, for many Elders who experienced colonial government institutions (e.g., residential schools, prisons), the formality of being asked to sign documents and provide government identification in exchange for cultural knowledge is insensitive and culturally inappropriate. Some participants advocated using verbal agreements or offering cash gifts.

DISCUSSION

Our study highlights the central role that Elders can hold in research done "in a good way" with Aboriginal communities.[39] Although finding the right fit or dealing with administrative frustrations that arise at the juncture of Indigenous and Western worldview practices is challenging, Elder engagement is essential for respectful community protocol and building bridges.

Our findings echo the results of others who write about the central role that Elders hold in Indigenous life as knowledge keepers, experts and teachers,[16,22,39–45] and credible carriers of information and translators of knowledge.[16,40,44,46] Elders have long been recognized for their important roles as ethical gauges,[12,42] with the skills to provide culturally safe counseling and support.[47]

This study recognizes the unique and specific role of Elders. It elucidates why many CBR projects engage Elders in research protocols, and may assist in discussions with research ethics boards and funders. It is also one of the first studies to highlight many of the important steps and culturally appropriate protocols for approaching Elders and finding the right fit for any given project. We intentionally identify the challenges of engagement to help research teams plan more effectively. Teams may want to frankly discuss gifting and honoraria possibilities with Elders and other community leaders at the outset of a study to ensure that culturally appropriate procedures are negotiated within reasonable budgetary and bureaucratic limits. Being transparent, forthcoming, and accommodating may help build solid relationships and avoid potential conflicts of interest. Moreover, although we highlight some of the challenges of finding Elders with anti-oppressive attitudes toward sexually diverse and drug-using communities, we also wish to acknowledge the roles that colonial intervention (e.g., church, state, residential schools) had in shaping many of these values. Traditionally, sexuality was not seen as shameful among many Indigenous communities.[48–50] Many Indigenous children were taught openly about their bodies, sexual and reproductive health, menstrual cycles, and relationships in rites of passage and coming-of-age ceremonies.[51] Today, many communities are trying to reclaim these customs.

We also reiterate that Elder engagement should not be seen as merely instrumental. Wilson eloquently argues that research is ceremony, and should be approached with appropriate respect and care.[52] He explains that Indigenous realities are shaped by relationships, and the space between is understood to be sacred. Ceremony bridges the space and helps build stronger relations. Research is a ceremony that brings a team closer to ideas. The ritual involves researchers demonstrating respect for Indigenous ways of knowing, preparing the space, bringing together the right actors, and engaging in ceremony. "When ceremonies take

place, everyone who is participating needs to be ready to step beyond the everyday and to accept a raised state of consciousness"[49(p69)] to deepen insights into the everyday world.

Limitations

Our study has several limitations. Our sample was qualitative and nonrepresentative, and results should be interpreted accordingly. We collected our data at a time of flux, when federal policies and guidelines about research approaches in partnership with Aboriginal communities were changing.[4,53] The study was not originally designed to address this research question (this was a secondary analysis), and key perspectives are missing. In particular, research is needed to examine the perspectives of Elders who have participated on research teams. Finally, all participants interviewed had been engaged in HIV CBR in a Canadian context. Still, we believe that the findings may be applicable to other public health research in North America, as well as HIV research in other parts of the world.[54,55]

Conclusions

Research practices are changing: Smith's call for decolonizing the research landscape has echoed around the world.[5] Many Indigenous communities are developing their own research councils that are demanding more inclusive research practices,[10,56] some universities are leading the way with new institutional policies and protocols for approaching and involving Elders,[57] and researchers are beginning to write practical guides for culturally appropriate engagement.[58] We are optimistic about possibilities for honoring more diverse knowledges in ethical public health research and practice. Mi'kmaw Elder Albert Marshall's teaches, "Knowledge is not a tool, but rather it is a spirit. It transforms the holder. It also reminds us that we have responsibilities to the spirit of that knowledge. We must pass it on."[59] Framed by Indigenous worldviews of knowledge production, Elder engagement becomes a vital part of the equation. ∎

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Contributors

S. Flicker, the principal investigator, facilitated team conversations, drafted the body of the article, and incorporated feedback into subsequent drafts. P. O'Campo, a coinvestigator, compiled the introduction. R. Monchalin conducted literature reviews. J. Thistle conducted the preliminary content analysis for the Results section. C. Worthington and R. Masching provided extensive feedback on multiple drafts. A. Guta conducted all the interviews and worked on revisions. Elders W. Whitebird and C. Thomas grounded the work in models of cultural safety, offered comments on the content, and provided overall guidance to the team. All authors participated in several conference calls to review coded data, define the scope of the article, assist with creating an outline, and offer feedback on several iterations.

Human Participant Protection

This study received ethical approval from York, Wilfrid Laurier, McGill, and Dalhousie Universities; the Universities of Toronto and Calgary; and St. Michael's Hospital.

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